

DOCUMENT RESUME

ED 112 583

EC 073 783

TITLE Position Papers of the American Association on Mental Deficiency 1973-1975.

INSTITUTION American Association on Mental Deficiency,
Washington, D.C.

PUB DATE [73]

NOTE 41p.

EDRS PRICE MF-\$0.76 HC-\$1.95 Plus Postage

DESCRIPTORS *Child Advocacy; *Civil Liberties; Drug Therapy;
Exceptional Child Services; Guidelines; *Mentally Handicapped; Normalization (Handicapped);
Professional Associations; Wages
*American Association on Mental Deficiency

IDENTIFIERS

ABSTRACT

Presented are the American Association on Mental Deficiency's position papers regarding the rights of retarded persons. Included are statements on the following topics: basic rights (such as freedom of choice and the right to the least restrictive individually appropriate housing); work by residents in private and public institutions (including right to compensation); protecting the lives of mentally retarded persons in cases involving the termination of life sustaining procedures; sterilization (including definitions of voluntary sterilization and legally incompetent persons); guardianship (including a discussion of the guardian's powers and duties); human rights review and protection boards; the right to habilitation (including an individualized program plan and compensatory rights); and the use of physical, psychological and psycho-pharmacological procedures to affect behavior of mentally retarded persons. (CL)

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POSITION PAPERS

of the

AMERICAN ASSOCIATION ON MENTAL DEFICIENCY

Approved by AAMD Council 1973 - 1975

American Association on Mental Deficiency
5201 Connecticut Avenue, N.W.
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COT 3783

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RIGHTS OF MENTALLY RETARDED PERSONS:

PREFACE

The American Association on Mental Deficiency supports the "Declaration of General and Special Rights of the Mentally Retarded" as adopted by the International League of Societies for the Mentally Handicapped, but recognizes the need to make statements more specific in nature and to make recommendations for action. Accordingly, the following document represents the Association's position on these matters, and is the Association's basic statement of policy. Future activities of the Association will be guided by this document, and will be directed to the fulfillment of its aims, in manners consistent with professional responsibility and professional opinion.

Professionals in the field, individually and in concert, should assert leadership in the protection of these rights, in assuring their exercise and enjoyment by retarded citizens, and in the implementation of these rights to provide for more satisfying circumstances of life for retarded persons.

The Association will pursue these goals through its regional and national organizations, through its publications, and through its membership in other groups.

The Association will also help to design, to promulgate, and to implement programs of preparation for professionals, paraprofessionals, and nonprofessionals that will facilitate their safeguarding and implementation of the rights of retarded persons as expressed in this statement. The Association will assist in the drafting of model legislation; will, on request, comment on and assist in the development of specific proposals for legislation that would affect retarded persons; and will participate, as appropriate, in legal proceedings of significant import and appropriate focus.

Professionals should bear in mind the statements in this document when preparing both general and individual programs for retarded persons, when designing facilities and organizing services for retarded persons, when taking part in the legislative process, when taking part in the judicial process, when considering the allocation of fiscal and other resources, when hiring workers, when seeking employment, when teaching, when conducting research, and most of all, when participating directly in the treatment, training, and habilitation of retarded persons. When a professional sees that retarded individuals are being dealt with in a manner inconsistent with the principles expressed in this document, then that professional person should act in a conscientious manner to remedy the situation immediately, through individual or group action, and by formal or informal process. This may be accomplished through job action, through administrative action, through legislative action, through judicial action, or through whatever public and private means are available, moral, ethical, and legal. The Association pledges to support such efforts in order to ensure the fullest exercise of professional skills and judgment on behalf of retarded persons. Association and individual action should be taken whenever an issue arises that affects the community of interests of retarded persons, whether that effect is direct or indirect.

Mentally retarded citizens are entitled to enjoy and to exercise the same rights as are available to nonretarded citizens, to the limits of their ability to do so. As handicapped citizens, they are also entitled to specific extensions of, and additions to, these basic rights, in order to allow their free exercise and enjoyment. When an individual retarded citizen is unable to enjoy and exercise his or her rights, it is the obligation of the society to intervene so as to safeguard these rights, and to act humanely and conscientiously on that person's behalf.

BASIC RIGHTS

I. The basic rights that a retarded person shares with his or her nonretarded peers include, but are not limited to, those implied in "life, liberty, and the pursuit of happiness," and those specified in detail in the various documents that provide the basis for governing democratic nations. Specific rights of mentally retarded persons include, but are not limited to:

A. The right to freedom of choice within the individual's capacity to make decisions and within the limitations imposed on all persons.

B. The right to live in the least restrictive individually appropriate environment.

Nonretarded adults have considerable latitude to control their own lives, particularly in terms of choosing place of employment and place of residence. Insofar as he or she is able to make these choices, a retarded adult should have the same freedom of choice. A classification of mental retardation is not, of itself, sufficient cause to restrict an individual's freedom of movement.

C. The right to gainful employment, and to a fair day's pay for a fair day's labor.

A retarded individual should be allowed to work at whatever job he or she is capable of performing and should be paid at a level reflecting his or her productivity. If a retarded person cannot work in the community at large, and is to be appropriately employed at the maintenance of the public or private institution at which he resides, then he also should be paid according to his level of productivity, and should receive appropriate fringe benefits. In no event should a retarded individual be retained at any facility solely because his or her presence enables the institution to maintain itself.

D. The right to be part of a family.

A retarded individual should not be summarily excised from his family, and should be permitted and encouraged to be with them whenever his developmental needs can be met satisfactorily in this manner. If he or she is an institutional resident, family visits should be encouraged, except when such contact may be detrimental to the individual's well-being.

E. The right to marry and have a family of his or her own.

Any retarded citizen who can be effectively self supporting, and who can be reasonably expected to discharge effectively the obligations of marriage and parenthood, should be permitted to marry and to raise a family, in no event, once a retarded person is married, should this marriage be annulled on the basis of the exclusive circumstance of mental retardation, nor should that person's right to bear and rear children be abridged. If a genetically transmitted condition exists, the retarded person should receive appropriate genetic counseling to ensure his understanding of the condition. If it should become evident that a retarded individual has become incapable of rearing his or her children, as may also occur with nonretarded parents, the same legal and professional procedures concerning parenthood that are applicable to families of nonretarded citizens should be applied to those of retarded citizens.

F. The right to freedom of movement, hence not to be interned without just cause and due process of law, including the right not to be permanently deprived of liberty by institutionalization in lieu of imprisonment.

If a retarded individual is brought to trial and ruled incompetent to defend himself, legal counsel must be provided, at public expense if necessary. A retarded person must not be remanded to any public institution interminably. When a retarded citizen has been judged to be incompetent to stand trial, that citizen must be provided an integrated, individualized, and comprehensive rehabilitative program. Regular judicial and programmatic review of an individual's program must be maintained.

G. The rights to speak openly and fully without fear of undue punishment, to privacy, to the practice of a religion, (or the practice of no religion), and to interact with peers.

A retarded individual should not be made to fear that interacting either exclusively with his or her retarded peers, or with members of society at large, will subject him or her to recrimination. Further, he or she must not be made to fear that complaint about or concern with the character of his or her public care will result in retribution. Every effort should be made for each retarded citizen to have time and space for his or her exclusive use.

SPECIFIC EXTENSIONS

II. Specific extensions of, and additions to, these basic rights, which are due mentally handicapped persons because of their special needs, include, but are not limited to:

A. The right to a publicly supported and administered comprehensive and integrated set of rehabilitative programs and services designed to minimize handicap or handicaps.

The retarded individual may reasonably expect a program of habilitation geared to his or her individual needs at public expense. This program of habilitation should recognize the individual's handicap(s), but should be geared to allowing that individual to function in a way as nearly as possible approximating the functioning of nonretarded citizens. Each individual, however severe his handicaps, should be helped to realize his maximum potential through an individualized rehabilitative program that takes maximum advantage of all relevant services, including social welfare services, medical services, housing services, vocational services, transportation services, legal services, and financial assistance services. The program should be subject to regular reevaluation and open review, and should be adapted to reflect the growth and learning of the retarded individual. For those severely handicapped individuals who may never be able to function independently, it is the responsibility of the larger society to provide effective and humane supervised care using the full spectrum of resources essential to the person's optimal development in the least restrictive setting consistent with the individual's capacities and needs.

B. The right to a publicly supported and administered program of training and education including, but not restricted to, basic academic and interpersonal skills.

The society must make every effort to enable its retarded citizens, from childhood, to learn and use the skills that are necessary to function in the least restrictive setting possible and to function in the community at large with the least supervision that is appropriate. Among the skills that retarded persons should be afforded the opportunity to learn are self help skills, money handling, use of transportation services, adaptive interpersonal behavior, reading, writing, the ability to take advantage of other services and sources of assistance in the community, and rewarding use of leisure time.

C. The right, beyond those implicit in the right to education described above, to a publicly administered and supported program of training toward the goal of maximum gainful employment, insofar as the individual is capable.

The public should provide a comprehensive set of appropriate programs of vocational training designed for retarded citizens. These may be provided through such situations as residential institutions, day care centers, sheltered workshops, vocational rehabilitation centers, or apprenticeship programs in the larger community. To the extent possible, government at all levels should attempt to see that positions are available for retarded individuals upon completion of their training, either in publicly sponsored programs or in private employment. Governments also should encourage the employment of retarded workers, by eliminating legal and other artificial barriers to their obtaining jobs.

D. The right to protection against exploitation, demeaning treatment, or abuse.

Retarded individuals should not be exploited, either by those who have been entrusted with their care or by members of the society at large. (Such exploitation in the past has frequently resulted from the individual retarded person's inability either to perceive the exploitative aspect of a situation or to defend himself or herself against it.)

E. The right, when participating in research, to be safeguarded from violations of human dignity and to be protected from physical and psychological harm.

In securing that right, it is essential that research with retarded persons be carried out only with the informed consent of the subjects (or, in very special cases, of their legal guardians), that retarded persons be made aware of their right not to participate, and that such research as may be done with retarded persons adhere to recognized contemporary standards of ethics and scholarship.

Nonparticipation in research must never be followed by aversive consequences or the threat or implied threat of aversive consequences. Given the limited ability of many retarded persons to comprehend the nature and possible risks of a research program, it is necessary that particular care be taken to assure that research subjects are truly informed on what is required of them, what risks (and possible benefits) are involved, and what will be done with the data. Investigators have a responsibility to confine their research with retarded persons to those studies whose outcomes are likely to bear some ultimate benefit to retarded persons.

The rights of retarded persons with respect to participation in research should be monitored and secured by some third party or group, rather than being left to the discretionary interpretation of individual scientists.

F. The right, for a retarded individual who may not be able to act effectively in his or her own behalf, to have a responsible impartial guardian or advocate appointed by the society to protect and effect the exercise and enjoyment of these foregoing rights, insofar as this guardian, in accord with responsible professional opinion, determines that the retarded citizen is able to enjoy and exercise these rights.

A retarded individual frequently requires the good offices and efforts of nonretarded citizens in order to have his or her welfare safeguarded. In most instances, this fellow citizen will be a member of the retarded individual's family. Occasionally, however, it becomes necessary to have an unrelated citizen or agency act in the retarded person's behalf. The appointment of such a guardian is generally made by the courts; the guardian may be responsible both for the retarded person's estate and for his person. Such appointments should continue to be made by the courts, but only with competent professional advice. The guardian of a retarded individual should not be a public official responsible for the direct and immediate care and management of that particular person.

It is the responsibility of the guardian to determine, in a manner consistent with reliable contemporary knowledge, the extent to which the individual with whose care he or she is entrusted can function independently, to determine the extent of that person's ability to enjoy and exercise his or her rights, and to seek the exercise thereof.

GUIDELINES FOR WORK BY RESIDENTS IN PUBLIC AND PRIVATE INSTITUTIONS FOR THE MENTALLY RETARDED

I. INTRODUCTION

For many years, public and private residential facilities for the mentally retarded have employed residents to accomplish a variety of tasks associated with the operation and maintenance of the facilities. Although residents frequently have not been paid for their services or have received only token compensation, work assignments have been considered to be both therapeutic for the resident and, at least in the case of public facilities, justified in terms of the cost to the state of providing residential services.

Enactment of the 1966 Amendments to the Fair Labor Standards Act¹ and the emerging recognition of the need to safeguard the individual rights of retarded persons have combined to force a reassessment of current policies and practices regarding working residents. The following guidelines have been developed both to facilitate the application of the 1966 Amendments to the Fair Labor Standards Act as they affect working residents in public and private institutions for the mentally retarded and to assist workers in the field in dealing with the issues involved. They are intended to maximize the social and economic protections afforded under the Amendments without jeopardizing *bona fide* training and treatment programs.

In preparing this document, the Association has been guided by the intent and spirit of the Declaration of Rights of the Mentally Retarded adopted by the United Nations General Assembly on December 20, 1971. Also inherent in this document is the belief that an institution should offer its residents the least restrictive work and living environment consonant with the individual's capabilities and habilitative needs.

II. GUIDELINES

- A. The mentally retarded individual has the same right to just compensation for his or her labor as any other citizen.

Therefore, all institutional residents performing work as defined in III G below (including work which is part of a program of occupational training) are entitled to remuneration commensurate with their productivity and in accord with current federal, state and local laws and prevailing wage rates for similar work in the surrounding community.

Commentary. The principles of equal treatment inherent in our constitutional form of government require that mentally retarded persons be offered the same basic rights as other citizens of the country. The right to just compensation for one's labor is a well established principle which should be applied to all mentally retarded individuals regardless of their place of residence.

- B. A working resident must be paid at least the prevailing minimum wage except when a separate certificate for a handicapped worker has been obtained by the facility in accordance with current regulations and guidelines issued under the Fair Labor Standards Act, as amended.²

Commentary. Existing regulations and guidelines issued by the U.S. Department of Labor should be interpreted to cover all handicapped workers regardless of whether they reside in an institution or in the community. Given the nature and severity of the afflictions of many institutional residents, it is recognized that their productivity may be only a small fraction of the average regular employee, nonetheless, such working residents deserve to be fairly compensated for their labor (see II C below).

- C. Any resident-performing work as defined in III G below must be compensated in direct proportion to his or her productivity as measured in work-equivalents of a regular employee's output.

Commentary. Compensation for handicapped working residents must be commensurate with those paid non-handicapped workers in nearby industry for essentially the same type, quality and quantity of work. The performance of each handicapped worker in the institution, whether compensated on an hourly or piece rate basis, must be related to: (1) the productivity which can be expected of an average non-handicapped worker if he were doing the same job, and (2) the prevailing wage in industry in the surrounding community for similar work or work requiring comparable skills. For example, if a working resident's productivity is about thirty (30) percent of normal output for an average non-handicapped worker and the prevailing wage rate is \$2.00 per hour, then he should be compensated in cash or in equivalent form of negotiable remuneration at a rate of 60 cents per hour ($.30 \times \$2.00 = \0.60).

- D. No resident should be permitted to engage in prohibited activities as defined in III J below.

Commentary: See discussion under III J below.

¹ The 1966 Amendments extended FLSA coverage to employees of public and private hospitals and nursing homes (including institutions for the mentally retarded) and altered the rules affecting handicapped workers in sheltered settings.

² At the present time five specific types of certificates authorizing subminimum wages for handicapped clients employed in sheltered workshops are available: regular program, work activities center, evaluation, training, and individual rate. A wage floor of at least fifty (50) percent of the prevailing minimum wage applies to all clients except those employed under work activities center, evaluation, training or individual-rate certificates. Individual-rate certificates may not be less than twenty-five (25) percent of the minimum wage. Work activities center, evaluation and training certificates establish no wage floor (Title 29, Part 525, Code of Federal Regulations, "Special Minimum Wages for Handicapped Workers in Sheltered Workshops").

E. Residents need not be compensated for self care and domiciliary activities as defined in III I below.

Commentary: Those tasks involving the resident's personal hygiene and care of the immediate domicile (e.g. grooming, bed making and sweeping) will not be considered work as defined in III G below when they are part of the individual's written habilitation plan. Therefore, compensation for such activities normally is not required (see also commentary under III I below).

F. When goods or products are produced on a piece rate basis by residents, the net profit from the sale must be returned to the residents in direct proportion to each individual's contribution to the production of such items.

Commentary: In determining the net profit from sale of resident-made goods or products, all direct costs to the institution connected with the production of such items may be deducted from the gross receipts from sales. When the costs to the institution exceed the receipts from sales, residents need not be compensated for their labor.

G. When any working resident is compensated monetarily for his labor and his quarterly earnings exceed the minimum requirement for social security coverage per quarter, he must be made eligible for social security, unemployment and workmen's compensation if such benefits are normally available to regular institutional employees.

Commentary: Under the conditions outlined above, a working resident should be entitled to the same social security, unemployment and workmen's compensation benefits as any regular employee of the institution. The same eligibility criteria for such benefits should apply to a handicapped working resident as applies to a regular employee of the institution, including the responsibility for paying the employee's share of social security taxes, as applicable.

H. All residents performing work as defined in III G below must be compensated at least one and one-half times the regular rate for all hours over 40 hours of labor in a work week in accordance with the provisions of the Fair Labor Standards Act, as amended.

Commentary: The principle of equal pay for equal work extends to payment for overtime work in accordance with the provisions of the Fair Labor Standards Act, as amended.

I. No resident who is under the legal working age as defined in applicable Federal and State child labor laws may engage in work as defined in III G below.

Commentary: Mentally retarded children should receive the same protection under applicable Federal and state child labor laws as any other affected minor.

J. When a resident is compensated monetarily, a portion of his wages may be withheld by the institution to recover an amount not to exceed the actual monthly costs incurred by the institution for care, treatment, training and maintenance of the particular individual. In determining the rate to be withheld from the resident's wages the following general rules will apply:

1. The resident may retain for his personal use an amount not to exceed twenty-five dollars or twenty-five percent of monthly earnings whichever is greater. However, in no case may the charge to the resident for care, treatment, training and maintenance exceed seventy-five percent of the working resident's gross monthly earnings.
2. The maintenance, care, training and treatment charge for any working resident must be based on the actual or approximate cost of providing food, lodging and ancillary services to that individual. In no case should an average per diem cost for the entire institution or similar across-the-board estimates be used in calculating charges to working residents.
3. In no instance may an institution charge any working resident from any one or combination of funding sources more than one hundred percent of the actual costs of providing board, lodging, care and treatment to that resident.

Commentary: The benefits and privileges of employment carry with them corresponding responsibilities. A working resident who is paid for his labor should be expected to reimburse the institution for board, lodging and ancillary services in accordance with his means. However, as indicated in II B above, frequently such residents will produce at only a fraction of the rate of the average regular employee. Thus, if this principle were literally interpreted, a large majority of working residents would receive no compensation for their labor since the actual cost to the institution of their maintenance, treatment and care would exceed the residents' earnings. In order to reinforce residents' work behavior through direct compensation for their labors, a ceiling is placed on the amount of the total earnings of any working resident which can be retained by the institution to cover the costs of board, lodging and supportive services. The twenty-five dollar monthly minimum is based on the amount that a Medicaid eligible resident will be entitled to receive for personal needs when the new Federal Supplementary Security Income program goes into effect next January.

In determining the cost of board, lodging and ancillary services, the institution should base such charges on the actual or approximate cost of providing such services to the particular resident. This provision is intended to guard against cost determinations based on institution-wide averages which would tend to exaggerate the actual cost of maintaining more capable working residents who generally will require a smaller investment of staff time and facilities.

The provision regarding multiple charges for board, lodging, care and treatment of any particular resident is intended to protect against situations where the institution recovers from several sources (Medicaid, Social Security, Trust funds, residents earnings, parental fees, etc.) more than one hundred percent of the actual costs of maintaining the resident in the facility.

- K. All monetary earnings and other income received by a working resident must be maintained in a secure account which is available to the resident for use at his discretion. The entire proceeds of the account, plus interest if applicable, should be returned to the resident upon his unconditional release from the institution.

Commentary. Any residual earnings (after taxes and reimbursement for the costs of lodging, board, and ancillary services) received by a working resident should be placed in a secure account which is accessible to the individual wage earner and available for his exclusive use. In no instance should the proceeds of an individual resident's account be lumped together in a general "patient benefit" fund or similar account which fails to identify that portion which belongs to the individual resident. When a resident is unconditionally released from the institution, he should receive the total balance remaining in his or her account plus interest, if applicable.

- L. Residents capable of involvement in the development of their own habilitation plans shall be provided the opportunity to participate in the selection of work situations which are within their capabilities. The institution should be responsible for counseling residents who are adjudged to be capable of performing work or engaging in occupational training on the positive benefits of such activities. However, no resident shall be coerced into working or engaging in occupational training or be punished for refusing to be involved in such activities.

Commentary. The institution has a responsibility to provide its residents with job counseling. Part of such a counseling program should include assisting the resident to understand and appreciate the positive benefits of occupational training and work. Whenever possible, residents should be offered a choice of work or occupational training settings as part of the development of his individual habilitation plan. However, should a resident refuse to work or engage in occupational training even after counseling, he should not be forced to do so or punished for refusing to participate in such activities. Withdrawal of any extra privileges normally offered working residents will not be considered punishment within the intent of this document.

- M. A resident in an occupational training program who does not show a significant increase in productivity over a six month training period, and who continues in the same activity, shall be considered to be performing work, and shall be remunerated accordingly.

Commentary. Occupational training, as defined in III F below, implies that the capabilities of the individual trainee to perform work are being improved and enhanced through an active training process. Once the overall performance of such a trainee has been stabilized, however, and he exhibits no significant increase in productivity over a reasonable period of time (six months), then he should be paid for his labor, placed in a new occupational training setting or transferred to another more appropriate habilitation program which does not involve work or occupational training. The purpose of this provision is to prevent the placement of a resident in an activity labelled occupational training for a prolonged or indefinite period of time.

III. DEFINITIONS

A. MENTALLY RETARDED INDIVIDUAL:

1. Any individual who meets the definition of mental retardation established by the American Association on Mental Deficiency.³
2. Any person so classified by any legal jurisdiction.

Commentary. These guidelines are intended to cover all persons found to be mentally retarded under the laws of any federal or state jurisdiction, plus any other individuals, not so designated, who meet the definition of mental retardation generally accepted by professionals in the field.

B. INSTITUTION:

An institution is any public or private residential facility of any size providing a constellation of professional services, on a twenty-four hour residential basis, including those directed toward the care, treatment, habilitation, and rehabilitation of the mentally retarded, and which exercises twenty-four hour control over these individuals.

Commentary. The key factor in determining whether a public or private residential facility meets the definition of an institution is the amount of control the facility exercises over the lives of the residents. An institution, as defined here, is one which exercises twenty-four hour control over the lives of the residents for whom it is responsible.

C. RESIDENT:

A resident is any mentally retarded individual, as defined in III A above, who resides at and is under the control of an institution as defined in III B above.

Commentary: Self explanatory.

D. REGULAR EMPLOYEE:

A regular employee is a person who works at an institution, is not a resident of that institution, as defined in C above, and who provides remunerable labor to the institution under Federal, state and local law.

Commentary: Self explanatory.

³ "Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifest during the developmental period." AAMD Manual on Terminology and Classification in Mental Retardation, 1973 Revision, Herber: J. Grossman, M.D., Editor; AAMD, p. II.

E. HABILITATION:

Habilitation includes any activity or a set of activities developed and supervised by qualified professionals which are intended to improve and maintain the health and the social, physical, and intellectual capabilities of a resident.

Commentary: An institution should maintain a written habilitation plan on each of its residents. This plan should outline an integrated, comprehensive and individualized set of specific program objectives for the resident. Each resident's plan should be reviewed periodically but not less than once annually.

When the individual's plan includes assignment to occupational training or work, specific statements of anticipated progress should be included in this plan along with the reasons for such assignments. When remuneration to a resident for work performed is to be in a form other than monetary payments, the reasons for using nonmonetary remuneration should be indicated in the individual's plan.

F. OCCUPATIONAL TRAINING:

Occupational Training is a specific time-limited category of habilitation which involves placement of a resident in a program which is designed to evaluate and/or enhance that resident's productive capacity and ability to perform in a competitive or protected work situation.

Commentary: It should be emphasized that occupational training is a goal oriented activity directed toward maximizing an individual resident's work capabilities. As such, occupational training should not be viewed as a permanent or unduly prolonged assignment for any resident. As indicated in II M above, any resident who fails to show a significant increase in productivity over a six month period while engaged in occupational training should be assigned to another, more appropriate, training or habilitation program; otherwise, the particular activity will be considered to be work within the meaning of G below.

G. WORK:

Work is any directed activity, or series of related activities, which benefits the economy of an institution, contributes to its maintenance, or produces a salable product.

Commentary: In deciding whether a particular activity constitutes work within the meaning of the above definition, the key determinant is: does the performance of the particular activity or function contribute to the economy of the institution. In other words, if residents were not available to perform the activity or function, would the institution be required to hire additional staff (or pay overtime to existing staff) in order to properly maintain the facility and carry out its assigned mission?

When a resident is engaged in producing salable goods and products on a piece rate basis, such activities will be considered to be work when the net profit from sales exceeds the costs to the institution connected with the production of such items (see II F above).

Under the definition, a resident engaged in an occupational training program may or may not be performing work as defined above depending on whether the particular activity or function contributes to the economy of the institution.

H. REMUNERATION:

Remuneration means money, or other forms of negotiable compensation, for work (including work performed in an occupational training situation), which is available to the resident-earner to be used at his or her discretion in determining the benefits to be derived therefrom.

Commentary: While monetary payment is the most commonly accepted method of reimbursing a worker for his labor, it is recognized that, under some circumstances, other forms of remuneration may be more desirable. However, under the above definition, any such non-monetary remuneration must be negotiable and permit the resident-earner discretion in determining the goods or services he wishes to obtain with his earnings. Intangible benefits to which it is difficult to attach a monetary value or benefits where the resident-earner has no chance to exercise a choice among alternatives will not be considered remuneration for work performed.

I. SELF CARE AND DOMICILIARY ACTIVITIES:

Self-care and domiciliary activities are tasks related to the care of one's own person and immediate domicile.

Commentary: To the extent of their capabilities, residents should be expected to perform tasks related to personal hygiene, grooming and care of their own immediate domicile. As indicated above, such tasks will not be considered work for purposes of remuneration. However, care and up-keep of the domicile, within this definition, will be limited to regular, routine tasks that a normal individual of similar age who lived in his own home might be called upon to perform.

J. PROHIBITED ACTIVITIES:

Prohibited activities are those work or occupational training activities which: (1) are unsupervised; (2) are supervisory; (3) are hazardous, either as defined under federal, state, or local law, or in light of an individual's functional capacities; and (4) involve the resident in the direct care of other residents, when the individual is neither qualified nor being trained for such an assignment.

Commentary: It is recognized that some activities which might not be viewed as hazardous to a normal worker, indeed may be quite hazardous for some working residents due to their physical or intellectual limitations.

Some residents might be trained, quite appropriately, for direct care of other, more handicapped residents in preparation for employment as a regular institutional aide or for placement in similar work in the community. However, care must be taken to assure that such tasks are assigned only under close supervision and as part of a structured training program; in addition, no unqualified resident should be permitted to engage in direct care of other residents.

PROTECTING THE LIVES OF CITIZENS WHO ARE MENTALLY RETARDED

Background

Over the past few years, there have been widely publicized reports of instances in which infants with surgically correctable conditions have been permitted to die because, in addition to their medical disorders, they were diagnosed, or suspected to be, mentally retarded. These infants were allowed to die by the conscious withholding of medical or surgical treatment.

In addition, bills have been introduced in several state legislatures which would permit physicians to withhold life-sustaining measures and authorize relatives to consent to such steps in the case of "terminally ill" patients including, at least by inference, severely mentally retarded citizens. Implicit in the arguments of proponents of these so-called "Death with Dignity" proposals is that the life of a severely handicapped individual is essentially meaningless and that they constitute a severe economic drain on the resources of their families and society.

As the oldest, and largest national organization representing workers in the field of mental retardation, the American Association on Mental Deficiency is deeply concerned about these developments and feels compelled to articulate its views on the right of every retarded person to a full life. This statement is intended to supplement and elaborate on an earlier Association policy statement concerning the basic rights of retarded persons.¹

Position

It is the position of the American Association on Mental Deficiency that the existence of mental retardation is no justification for terminating the life of any human being or for permitting such a life to be terminated either directly or through the withholding of life-sustaining procedures.

Discussion

In developing the above position the Association has taken into account the following considerations:

1. It is a basic tenet of our American constitutional system that all citizens are entitled to equal rights under the law. The right to preservation of life is among the basic protections guaranteed to every citizen under the Constitution of the United States. Therefore, it follows that all citizens, including the mentally retarded, should have equal access to current medical, surgical, social and other life-sustaining procedures and be recognized as human beings with value and meaning to their lives, regardless of their diagnosis or prognosis.
2. The rapid expansion in professional knowledge and technology is making it possible for more retarded persons to improve their capabilities. For example, it has been repeatedly demonstrated that the severely and profoundly retarded can benefit from habilitative services and, thus, enjoy fuller and more rewarding lives than once thought possible.

¹ Rights of Retarded Persons.

3. With the exception of certain classes of criminals, as a society we have established no ethical basis for deciding who should live and who should die. Criteria for evaluating the relative worth of a human life simply does not exist. Therefore, any attempt to determine individual worth on the basis of economic or social consideration is invalid.

STERILIZATION OF PERSONS WHO ARE MENTALLY RETARDED

I. Introduction

Mentally retarded persons have the same basic rights as other citizens.¹ Among these rights are the rights, in conformance with state and local law, to marry, to engage in sexual activity, to have children and to control one's own fertility by any legal means available. Since sterilization is a method of contraception available to most North American adults, this option should be open to most retarded citizens as well.

However, recent reports on cases involving the sterilization of mentally retarded individuals without even the most elementary legal and procedural safeguards raise serious questions concerning the adequacy of current efforts to protect the human and constitutional rights of such citizens. Indications that retarded persons have been involuntarily rendered incapable of procreation because of presumed social irresponsibility, real or supposed genetic defects, or as a quid pro quo for release from an institution or receipt of financial assistance and social services are deeply disturbing, to say the least.

The American Association on Mental Deficiency is pleased that various legislators, governmental agencies, and a few other professional organizations have begun to speak out on the issue of sterilization. We believe it is our obligation, as the oldest and largest organization of professionals in the field of mental retardation, to make known our position on the matter, especially as it relates to mentally retarded persons.

II. Definition of Terms

A. Sterilization: A surgical procedure, the primary purpose of which is to render an individual incapable of procreating without impairing his or her capacity to engage in sexual activity.

Commentary: Sterilization, as presently practiced, differs from other methods of contraception in that its effects are usually permanent. Reversal requires additional surgery which is not predictably successful.

In the medical context sterilization is considered an elective procedure; the consequences are major, although the surgery itself is frequently minor.

B. Voluntary Sterilization: Refers to the performance of a sterilization procedure with the informed consent of the patient, or, where the patient cannot give "informed consent," but would presumably do so if competent, with the concurrence of his or her personal representative (acting as a surrogate) and a court, acting in his or her interest.

Commentary: Currently (as of February, 1974), no jurisdiction has a statute prohibiting voluntary sterilization.² Such procedures are governed by the same

¹ See Rights of Mentally Retarded Persons.

² Based on information supplied by the School of Law, University of Miami.

general legal, ethical, and professional considerations which apply to other forms of elective surgery. These considerations include informed consent, confidentiality of the patient-physician relationship, and the right and duty of the physician to refuse treatment which he or she believes is illegal, unethical, or medically unnecessary.

C. Involuntary Sterilization: refers to legally authorized sterilization of an individual without his or her consent, generally following professional review procedures set forth in law, but which is not voluntary as above defined.

Commentary: Twenty-one states currently have statutes permitting involuntary sterilization. Most such laws were enacted in the early part of the twentieth century, and had "protection of society," rather than of the individual, as their justification; in recent years, however, there has been a marked decline in their application to mentally retarded persons.

D. Legally Incompetent Person: an individual who has been so adjudicated by a court of competent jurisdiction.

Commentary: Declarations of incompetence are ordinarily made by courts upon the advice of professionals. Persons so declared usually have guardians appointed by the Court to act in their behalf. Minors are generally considered incompetent under the laws of most states. The age of consent, which may be different from the age of majority in some states, is sometimes used as one basis for determining competence.

E. Person of Impaired Capacity: An individual who has not been formally declared incompetent, but: (1) on the basis of professional assessment, is found to be sufficiently mentally impaired so as to be unlikely to make a reasoned and informed judgment about an issue as grave as sterilization; or (2) while possessing the mental capacity to make an informed judgment, is under some form of confinement or duress which limits his or her freedom to exercise such judgment.

Commentary: Within our society, there is a significant group of persons, who, while never adjudged legally incompetent, in fact lack the mental capacity to form a reasonable decision on serious issues such as sterilization. A second group of individuals also fall within our definition of a "person of impaired capacity." These individuals may possess the intellectual capability to make reasonably complex decisions on their own behalf but are under the control of or dependent upon an institution, agency, or individual for their support or survival. In such cases, the individual's freedom to exercise unrestrained judgment is restricted by the nature of his or her dependence on the provider agency or individual. For example, regardless of how benevolent the purposes and practices of a public or private residential facility for the mentally retarded may be, the individual resident is constrained by his or her dependence on the facility for treatment and daily sustenance and, as such, is a person of "impaired capacity." There should be no presumption of incompetence (or of competence) associated with the designation of an institutionalized person as "impaired."

F. Court: Usually refers to a state court having jurisdiction in matters of competence and/or commitment of mental patients; however, the term, as used here, may also be construed to mean an administrative review board, authorized by statute, provided at least one member is an attorney and at least one member is a professional qualified in the clinical and social evaluation of mentally retarded persons.

III. Guidelines

A. Involuntary Sterilization: The American Association on Mental Deficiency strongly opposes the enactment and application of statutes that permit involuntary sterilization.

³Ibid.

Commentary: State statutes authorizing the involuntary sterilization of retarded persons are generally based on false and outmoded beliefs about the genetic mutability of mental retardation which were prevalent in the early part of this century. AAMD, therefore, favors the repeal of existing involuntary sterilization statutes affecting the mentally retarded and strongly discourages the application of such laws.

B. Voluntary Sterilization: In order to facilitate protection of the rights of retarded citizens, and to guard against the possibility of imposing unwanted or unnecessary sterilizations, the general population can be divided into three classes: (1) competent persons or persons who are presumed to be competent; (2) legally incompetent persons; and (3) persons of impaired capacity.

1. Competent Persons: The competent person, or the person who is presumed to be competent, should have the right to exercise free and informed choice, without coercion or constraint, in the selection of contraceptive methods. Such an individual is not distinguished from any other citizen and therefore should be free to initiate the decision to control his or her own fertility and to elect the contraceptive method to be used, if any. Before such a person elects sterilization, the following conditions should be met:

a. He or she should be free from involuntary constraints, such as commitment or legal custody, and possible expressed or implied inducements or contingencies which are controlled by other individuals, agencies, or organizations.

b. Prior to reaching a decision, each individual should be informed about, and have access to, other less restrictive alternative forms of contraception. When other forms of contraception are provided they must be offered under circumstances which favor their effective use.

c. Prior to electing to be sterilized, the person should have a full explanation of the nature and likely consequences of the sterilization procedure and an opportunity to signify his or her understanding. If the person is unable to read, a verified record or transcription of the essential features of the oral interchange should be maintained.

Commentary: The intent here is to assure the maximum possible participation of an individual in decisions regarding his or her reproductive capacity. Therefore, the most rigorous guarantees possible of this participation are to be exercised. For example, an illiterate person might be competent to make a decision regarding sterilization; in this case a simple written transcript would be insufficient, and procedures and other assurances should be followed to prevent any possibility of the individual's not participating fully in the decision.

2. Legally Incompetent Persons: A legally incompetent person should never be sterilized involuntarily, and should be voluntarily sterilized only in those exceptional circumstances which have been reviewed and approved by a court of competent jurisdiction. Such court proceedings should be conducted in a manner designed to afford the individual all the procedural safeguards necessary to protect his or her individual rights. In conducting its work, the court should review and affirm that all of the following conditions have been met.

a. The individual is presumed to be physiologically capable of procreation;

b. The individual is or is likely to be sexually active in the near future.

c. Pregnancy would not usually be intended by a competent person facing analogous choices;

d. Less drastic alternative contraceptive methods have proved unworkable or are inapplicable;

- e. The guardian of the person agrees that sterilization is a desirable course of action for his or her ward;
- f. The Court has received advice based on a comprehensive medical, psychological, and social evaluation of the individual;
- g. The person is represented by legal counsel with a demonstrated competence in dealing with the medical, legal, social, and ethical issues involved in sterilization;
- h. The person, regardless of his or her level of competence, has been granted a full opportunity to express his or her views regarding sterilization and these views have been taken into account in determining whether to sterilize the individual.

Commentary: An individual who is incompetent should not be denied access to sterilization; however, the legal, social, ethical, and professional safeguards outlined above should be applied rigorously to assure that the best interest of the retarded individual remains paramount in the decision-making process.

3. Persons of Impaired Capacity: Persons of impaired capacity, as defined in II, E, above, should not be sterilized, except with the approval of a court of competent jurisdiction. The same conditions set forth for sterilization of legally incompetent persons under III, B, 2, above, should apply, except that the additional approval of the next of kin (or if lacking such kin, of a guardian ad litem) should be substituted for the consent of the legal guardian of the person, if there is no legal guardian other than a public official.

Commentary: It is the intent of this guideline to ensure that retarded persons are afforded adequate safeguards against unwanted or unnecessary sterilizations. Therefore, where doubt exists as to whether the individual is capable of exercising an informed judgment or is under some form of custody or duress, the individual should be considered a "person of impaired capacity," and thereby afforded the additional protections offered under this guideline.

GUARDIANSHIP FOR MENTALLY RETARDED PERSONS

I. Introduction

In its basic policy statement on the "Rights of Mentally Retarded Persons," the American Association on Mental Deficiency recognized that some retarded individuals will require the assistance of a guardian in order to exercise and enjoy fully their legal and human rights. That statement says, in part, that "...a retarded individual who may not be able to act effectively in his or her own behalf has a right to have a responsible impartial guardian or advocate appointed by the society to protect and effect the exercise and enjoyment of his, or her rights..."

Guardianship is a legal relationship whose essential purpose is to replace the disabled individual's legal authority to make personal decisions in his or her own self-interest when the individual does not have adequate natural capacity to make such decisions for himself or herself. At the same time within the guardianship process the first basic right of the mentally retarded person would be honored. This is "the right to freedom of choice within the limitations imposed on all persons."¹ To the maximum extent of their capabilities, retarded persons, whether under guardianship or not, should be permitted to participate as fully as possible in all decisions which will affect them.

Guardianship can be compared to a physical prosthesis which replaces a naturally functioning member. Excising the member (in this case the legal right of the individual to certain elements of self-determination) should not be undertaken until it is clear that a substitute member, in fact, will give the individual a fuller functional capacity for social living. Like an artificial leg, guardianship necessarily operates in a manner somewhat different than the function it replaces and may even have some advantages which partially compensate for the basic loss of the natural function. In fitting a prosthesis the surgeon makes every effort to conserve the remaining natural functions.

Similarly, in appointing a guardian the responsible body ideally should seek to preserve for the ward the opportunity to exercise those rights which are within his comprehension and judgment, allowing for the possibility of error to the same degree as is allowed to persons who are not retarded.

In the past, American society has failed to take full cognizance of the special needs of retarded persons in the establishment of guardianship systems. Thus, the guardianship statutes of most states and provinces are designed with emphasis on safeguarding the ward's property. Only recently have the peculiar needs of retarded adults for personal and social supervision begun to be recognized.

Those whose incompetence is due to mental retardation have certain characteristics which tend to differentiate them from persons who become senile or suffer an episode of mental illness. Some of these characteristics are the following:

- Having grown into adulthood without experiencing a normal childhood or normal adult independence, the retarded person tends to accept continuation of the status of dependence.

¹ See Rights of Mentally Retarded Persons.

- The adult whose retardation is manifest in a significant degree of social incompetence can expect to continue to develop and mature, but at the same time to require continued assistance in decision making and protection from exploitation; this prospect is of very long duration.
- The retarded person is likely to have relatively low, if any, earnings and consequently is unlikely to accumulate the assets which in the past have given rise to the appointment of a guardian of both the person and property.
- The incompetent retarded adult is likely to remain single and hence less likely to have a spouse or children to attend to his or her needs; thus he is more vulnerable as his parents become older.

The purpose of this statement is to articulate a set of principles upon which an improved guardianship system can be based - one which takes into account the special needs of retarded persons in an affirmative manner.

In order to have an improved guardianship system it is necessary to have:

- (1) reform of procedures which assure "due process" in a manner which is both responsive and practical;
- (2) substantive machinery to assure that any person who needs guardianship will in fact have the continuing assistance of a conscientious well-oriented individual.

The National Conference of Commissioners on Uniform State Laws and the American Bar Association recently developed a proposed Uniform Probate Code² which, in Article V, covers "Protection of Persons Under Disability and Their Property." These recommendations, if followed, would effect many of the procedural changes necessary to implement the principles proposed in this position statement. In particular, the Uniform Probate Code would:

- (1) distinguish more clearly between guardianship of the person and conservatorship (of the property) both as to functions and as to the degree and character of disability which justifies their use;
- (2) place reliance on the discretion of the guardian or conservator unless expressly limited by the court;
- (3) emphasize provisions designed to avoid the necessity of guardianship or protective proceedings; for example, the proposed language expressly permits the court to intervene directly in short term or one time decisions affecting property where the appointment of a conservator would be unduly cumbersome;
- (4) expressly authorize testamentary nomination of a guardian or conservator by a spouse or parent;

² Joint Editorial Board for the Uniform Probate Code. Uniform Probate Code. St. Paul, Minnesota: West Publishing Company, 1974 Edition.

- (5) permit a guardian who is not also a conservator to receive and dispense moderate amounts of income, etc., used for the benefit of the ward.
- (6) consolidate "regular" guardianship with "veterans" guardianship.

II Definitions

- A. Advocate. A person who promotes the interests of another.
- B. Beneficiary. The person who benefits from an established trust.
- C. Conservator. A person who is appointed by a court to manage the estate of a protected person.
- D. Fiduciary. A general term for a person entrusted with the property or interests of another. It includes conservators, guardians, trustees, etc.
- E. Guardianship.³ A legally recognized relationship between a competent adult (the guardian) and a minor child or incapacitated adult which lays upon the guardian the duty and right to act on behalf of the ward in making decisions affecting his or her life.
- F. Incapacitated person.⁴ Any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advance age, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his or her person.
- G. Legal guardianship. Guardianship established by a court (or other authorized administrative body) after a determination that the ward is incapacitated.
- H. Minor ward. A minor for whom a guardian has been appointed solely because of minority.
- I. Natural guardianship. The relation of a parent to his or her minor child.
- J. Protected person.⁵ A minor or other person for whom a conservator has been appointed or other protective order has been made as a result of a disability.

³ Traditionally guardianship has included guardianship of the person and guardianship of the property. All states have guardianship statutes; however, terminology differs; many still use "guardian" to include "conservator." Other terms used in some states include "curator," "committee," etc. In this statement the Uniform Probate Code usage which defines "guardian" so as to equate it to "guardianship of the person" will be followed.

⁴ The Uniform Probate Code discontinues the use of "incompetence" as a legal term and uses instead the concepts of "incapacitated person" and "protected person."

⁵ See footnote 4.

K. Protective proceeding.⁶ A proceeding to determine that a person cannot effectively manage or apply his estate to necessary ends, either because he lacks the ability or is otherwise inconvenienced, or because he is a minor, and to secure administration of his estate by a conservator or other appropriate relief.

L. Trustee. One entrusted with managing assets for another under the terms of a trust. The trust may be established by the donor for the benefit of himself or someone else.

M. Visitor. With respect to guardianship proceedings, a person who is trained in law, nursing or social work and who is an officer, employee or special appointee of the court with no personal interest in the proceedings.

N. Ward. A person for whom a guardian has been appointed as a result of an incapacity.

III General Principles

A. Since conservatorship or guardianship necessarily denies an individual the right to exercise freely certain personal liberties, every effort should be made through the use of social counseling services to prevent the need for appointment of a guardian or conservator (or both).

B. No mentally retarded adult should have a guardian appointed unless (1) he or she is found to be significantly lacking the social competence necessary to make critical decisions respecting the conduct of his or her life; (2) the appointment of such a guardian will be in the best interest of the person and the community, and (3) procedural due process has been observed in reaching these findings.

C. To the maximum extent of their capabilities, retarded persons, whether under guardianship or not, should be permitted to participate as fully as possible in all decisions which will affect them.

D. Retarded adults who cannot assert their own rights should have individual guardians appointed, regardless of the setting in which they are living.

E. Retarded children who lack parental supervision or support should have guardians appointed in the same manner as similarly situated minor children who are not retarded.

F. The boundaries of a specific guardianship should be specified, taking full cognizance of the social competencies and limitations of the individual ward. In other words, the guardian's mandate should be prescriptive in nature permitting the retarded adult to act in his own behalf on all matters in which he is competent.

6 Section 5-401 of the Uniform Probate Code provides that "appointment of a conservator or other protective order may be made in relation to the estate and affairs of a person if the court determines that (i) the person is unable to manage his property and affairs effectively for reasons such as mental illness or disability, advanced age, chronic use of drugs, chronic intoxication, confinement, detention by a foreign power, or disappearance; and (ii) the person has property which will be wasted or dissipated unless proper management is provided, or that funds are needed for the support, care and welfare of the person or those entitled to be supported by him and that protection is necessary or desirable to obtain or provide funds."

G. Particular care should be taken that retarded adults are treated like adults, and not like children, even when they are under guardianship.

H. All clinical judgements as to an individual's competence should be based on a careful evaluation conducted by a multi-disciplinary team. In no event should an evaluation of social competence be based on the judgement of a single professional.

IV Powers, Duties and Qualifications of the Guardian or Conservator

The specific duties of a particular guardian will vary according to the individual competencies and limitations of the ward (see III, F, above) and the capacities of the guardian. Duties of guardianship and conservatorship may be separated or assigned to the same fiduciary.

A. Powers of the guardian. Although the powers of the guardian may be limited by the appointing authority in order to permit the ward to exercise his residual capacities to make his own decisions, the powers accorded to the guardian in the area of his responsibility should be sufficiently inclusive to enable him to act promptly and effectively and "normally" in the interest of his ward. He should therefore, in general, have authority to expend funds for routine purposes beneficial to the ward, to give informed consent for medical and surgical care, and to apply for admission of his ward to those community and residential services which, after professional consultation, he deems most appropriate, provided such facilities meet certain standards which assure appropriate independent evaluation of the need for such admission, and the quality of care.

The following criteria apply to the guardian's exercise of his major powers:

1. Admission to facilities

- a) If the facility is of a type which is subject to licensure it should be licensed, and preferably accredited.
- b) If the facility is of a type which could be certified for care of persons who are eligible for federal support under such programs as "Medicaid" and "Medicare", it should be so certified even though the ward may not himself be eligible for these benefits.
- c) If the facility is a residential facility it should have policies and procedures relative to admission which meet the criteria of Accreditation Council for Facilities for the Mentally Retarded, Joint Commission of Accreditation of Hospitals, or its equivalent for admission and release.⁷ Such policies and procedures are designed to assure (1) that a comprehensive evaluation of the retarded person's needs and the alternatives for meeting them has been made and (2) that the placement is considered to afford the optimum available program plan for the individual. This includes the concept of "least drastic alternative."

7 See Section 1.3, Standards for Residential Facilities for the Mentally Retarded (as revised), Joint Commission of Accreditation of Hospitals, 1971.

2. Informed consent

- a) In giving informed consent on behalf of his ward, the guardian should be entitled to full information, including information on care, treatment and training alternatives. Informed consent by the guardian to experimental procedures should be subject to the restrictions established by the United States Public Health Service regardless of whether federal funds are involved.

3. Expenditure of funds

The Uniform Probate Code calls for appointment of a conservator when the ward's property requires "management" or when the ward has dependents, but states that if none have been appointed the guardian may receive money and tangible property and will apply them to the ward's needs. If there is a conservator the guardian still has responsibility for decisions regarding "current expenses."

When a disabled or incapacitated person's assets are held in trust it may not be necessary to appoint a conservator; on the other hand, it may prove useful to appoint the trustee as conservator if the beneficiary also has property not in trust. Where the trustee is an individual and the beneficiary is incapacitated it may be desirable for the trustee also to seek the status of guardian; where the trustee is a bank, it will usually be desirable to have an individual appointed to serve as guardian of an incapacitated beneficiary.

4. Court review

A decision of a guardian on behalf of his ward may be reviewed by the appointing court on its own initiative or on petition of a near relative of the ward, or on petition or recommendation of a qualified mental retardation professional or public interest attorney.

The above criteria are consonant with the Uniform Probate Code.

B. A guardian (of the person) should

1. interact regularly with the ward;
2. allow the ward to make as many decisions as possible and participate as meaningfully as possible in other decisions affecting his or her life;
3. serve as an intermediary or interpreter for the retarded person in his or her interaction with social institutions;
4. enlist professional expertise where necessary (physician, lawyer, etc.);
5. assure that the ward fulfills all civil duties;
6. act on behalf of the ward in securing personal and civil rights;

7. select and mobilize needed community resources on behalf of the ward;
8. keep track of the ward's progress in service programs and assure that his or her civil liberties are being adequately safeguarded;
9. conform to all requirements of the appointing court.

C. A conservator should

1. oversee the handling of any financial assets the ward may have and assure that all financial decisions are made in the best interest of the ward;
2. cooperate with the guardian (of the person) providing funds needed to pay for appropriate services, etc.

D. Prerequisites for guardianship appointments

To be selected as a guardian, an individual should possess the following qualities;

1. should be able and willing to perform the duties specified above;
2. should be able to maintain the best interests of the retarded ward as the paramount consideration in all decisions made on his or her behalf;
3. should have no conflict of interest; individuals who have personal-financial interest in the ward or are professionally responsible for providing or supervising his or her care or treatment should not be appointed guardians under any circumstance; however, this consideration should not preclude appointment of parents, natural or adoptive, or other close family members where otherwise suitable;
4. should be accessible - i.e., in close enough physical proximity and not so overburdened with other duties that he or she is unable to interact regularly with his or her ward;
5. should be in a position to serve as guardian over a reasonable period of years.

E. Recall statutes should include provisions for recall for non-feasance, malfeasance, death, incapacity, etc., and for expeditious appointment of successor guardians (see Uniform Probate Code).

V. Determination of Need for Guardianship

"Due Process" in determining the need for guardianship requires that this need be reviewed by a judicial body or by a designated administrative tribunal or panel which observes due process and whose findings are subject to appeal to a court. If a court is given the responsibility directly, preference should be given to a family court. In either case the body (court or tribunal) should have its own resources for obtaining advice and information which will permit its members (1) to develop an informed opinion as to the social characteristics of the mentally

retarded subject and the nature of his need for legal enablement through guardianship, and (2) to select an appropriate person to serve in the capacity of guardian. If the tribunal consists of several persons drawn from the fields of behavioral science and law, with experience in mental retardation, then the need for back-up staff will be less than if the body is a court of general or probate jurisdiction.

The basic responsibility of the court or tribunal is:

- A. To determine the extent of the prospective ward's impairment in adaptive behavior ("incapacity") and his consequent need for a surrogate decision maker and advocate to act on his behalf in respect to some or all major decisions affecting his life.
- B. To select and appoint an appropriate guardian from among possible guardians; private or public.
- C. To describe (in a written charge) the extent and scope of the guardian's duties and authority vis-a-vis the particular ward.

As a general principle, the charge to the guardian should respect the discretion of the guardian in those areas not reserved to the ward, with a minimum of detailed review (other than periodic review) by the guardianship agency or the court or tribunal (see IV above).

The general functioning of guardians and the guardianship system should be evaluated and monitored by the guardianship agency as described in VI below.

In the process of determining the need for guardianship, the court or tribunal should assure the prospective ward the right to:

- (1) have a full, fair and impartial hearing;
- (2) have independent legal representation during all stages of all proceedings;
- (3) have access to all records and documents presented to the tribunal or court which bear on his case;
- (4) receive an explanation in clear, nontechnical language, of his or her rights and the purpose of the hearing;
- (5) be present at the hearing and be heard;
- (6) appeal the tribunal or court's decision to a court of higher jurisdiction;
- (7) have his or her need for continuing guardianship reviewed periodically by the court or tribunal. Prior notice of such proceedings should be sent to all interested parties and cross-examination should be permitted.

VI. Guardianship Agency

In order to facilitate the recruitment, training, appointment and supervision of individual guardians, a guardianship agency should be established in each state of the United States and province of Canada. The general functions and organizational prerequisites of this agency are provided below:

A. Functions of the Guardianship Agency

1. Recruitment, training and submittal of recommendations on potential guardians;
2. Supervision and monitoring of guardians;
3. Review of the reports filed by guardians (in accordance with rules set out by the court or agency) and taking all necessary actions based on an analysis of such reports;
4. Investigation of individual cases, either in response to complaints or on a random sample basis, to determine the adequacy of existing guardianship arrangements;
5. Conduct outreach activities (e.g., community education, identifying retarded persons who may be in need of guardianship, etc.)
6. Furnish necessary technical assistance and back-up services to guardians;
7. Assure that individual counseling services are provided through existing service agencies in order to minimize the number of persons requiring guardianship services;
8. Gather information on the overall guardianship system and evaluate its effectiveness;
9. Provide personnel to the courts, as requested, to serve as "visitors". (Section 5-308, Visitor in Guardianship Proceeding, Uniform Probate Code.)

B. Organization of the Guardianship Agency

1. The agency should be administratively and fiscally independent of any public or private agency responsible for the delivery of direct services to mentally retarded persons.
2. The agency should be adequately financed and staffed (both qualitatively and quantitatively) to carry out its functions. The agency's permanent staff should be drawn from a variety of professional disciplines.
3. The responsibilities of the agency should be sufficiently decentralized so that agency representatives can interact directly with individual guardians and have an opportunity to observe, first-hand, the day-to-day operation of the guardianship system throughout the state or province.

VII. Support Activities

- A. Schools of Law throughout the country should be encouraged to:

1. Include more social scientific information about mental retardation in their curricula;
 2. Foster activities in which law students come into direct contact with a diversity of mentally retarded persons and with professionals who work with them;
 3. Cooperate in research related to methods for determining and validating relative social competencies among mentally retarded individuals; and
 4. Undertake comparative analyses of various guardianship systems, both nationally and internationally.
- B. Schools of Social Work, Medicine, Education and other appropriate university units, including University Affiliated Facilities, should include additional curricular material relative to rights of minors and incompetent persons and on the constitutional basis for due process procedures, family law and related legal principles. Students in human services should be brought in contact with law students and faculty in "real life" situations.

HUMAN RIGHTS REVIEW AND PROTECTION BOARDS

I. Introduction

Vulnerability to rights violations varies depending upon economic and social group membership. Mentally retarded individuals are especially susceptible to infringement of their rights.

In its basic policy statement on the "Rights of Mentally Retarded Persons" (October, 1973) the American Association on Mental Deficiency makes clear that professional persons have a moral and ethical responsibility for providing leadership in protecting the rights of retarded persons. The statement says, in part, "Professionals in the field, individually and in concert, should assert leadership in protection of these rights, in assuring their exercise and enjoyment by retarded citizens, and in the implementation of these rights to provide for more satisfying circumstances of life for retarded persons."

One of the difficulties faced by individual practitioners and interested professional and citizen groups, however, is the lack of a clear focal point within our society for protecting the legal and human rights of retarded children and adults. The purpose of this policy statement is to suggest a general strategy for addressing this issue.

II. Guidelines

A. Establishment of Human Rights Review and Protection Boards

In order to safeguard adequately the legal and human rights of mentally retarded persons, a network of human rights review and protection boards should be established in each state of the United States and each province of Canada. The main purpose of these boards will be to assure that proper legal, administrative, and procedural safeguards are available to protect the individual rights of mentally retarded persons.

Commentary: While the scope of the boards' activities and organizational configurations may vary significantly from state to state, each board should perform the essential functions and be organized in accordance with the general principles outlined below. Among the factors which will have to be taken into account in organizing a statewide network of boards are: (a) the physical size of the state and other geographical considerations; (b) population; (c) the structure of the existing service delivery system, including defined sub-state service areas; and (d) any other relevant social and political factors.

B. Functions of the Board

Each board should perform the following essential functions:

1. Review, monitor and assess the efficacy of existing and proposed methods and procedures for protecting the rights of mentally retarded individuals;
2. Review and comment on proposed legislation, regulations, guidelines, and standards for licensure insofar as they affect the human rights of retarded individuals.

3. Serve as an independent review body responsible for investigating alleged violations of the rights of individuals and groups brought by retarded persons, their parents or guardians, or other parties;
4. Assure that all service agencies have formal due process appeals procedures through which retarded persons or their representatives can raise complaints concerning alleged infringements of their rights and receive a prompt and fair hearing before the board;
5. Bring to the attention of appropriate agencies existing violations of human rights;
6. Perform periodic on-site inspections of programs serving the mentally retarded to assure that the rights of all clients are being adequately protected.

Commentary: Human Rights Review and Protection Boards are not intended to deny any individual the right to seek redress in the courts. On the contrary, the boards should be reviewed as an administrative means of identifying actual or potential rights violations and seeking appropriate corrective action before formal litigation becomes necessary. The boards would also be responsible for advising legislators and agency administrators on the adequacy of rights safeguards built into statutes, regulations and agency operating policies.

Since its primary role is administrative, a board should not initiate, sponsor or otherwise directly engage in litigation; however, individual board members, acting independently of the board, may choose to play an active role in cases before the courts.

III Organizations of the Boards

In organizing the proposed boards the following general principles should be followed:

1. The board should be administratively and fiscally independent of any public or private agency responsible for the delivery of direct services to mentally retarded persons;
2. The board should be so positioned within the state, regional or local structure of government as to have ready access to key decision makers in each of the major component parts of the service delivery system;
3. The board should have free access to the records of agencies serving the retarded within their jurisdiction except that confidential, personal records should not be released unless authorized by the client, the client's legal representative, or the courts.
4. The board should be adequately financed and staffed (both qualitatively and quantitatively) to carry out its functions. The board's permanent staff should be drawn from a variety of professional disciplines;
5. A cross-section of major viewpoints on the needs and rights of retarded citizens should be represented on the board. The membership of the board should include a qualified attorney, consumers, consumer representatives, and professionals from a minimum of three associated fields such as social work, education, psychology and medicine.

Commentary: While a board must be prepared to speak out forthrightly against administrative policies or professional decisions which infringe on the rights of retarded persons, its purpose is not to second guess the professional judgment of individual practitioners regarding the most appropriate treatment modalities or intervene in the day-to-day administrative decisions of program officials except as they impinge on the exercise of the legal and human rights of mentally retarded individuals. In addition, the board should function as a corporate body and not as a vehicle for airing individual grievances, concerns or programmatic viewpoints of individual members of the board.

THE RIGHT TO HABILITATION FOR PERSONS WHO ARE MENTALLY RETARDED

I Introduction

Over the past twenty years, American society has learned that any serious attempt to ameliorate the consequences of mental retardation, of necessity, must involve the synchronized efforts of a variety of health, education and social service specialities. Providing this wide array of needed services in a comprehensive, balanced system, however, has proven to be an elusive goal.

Fragmentation of services and lack of proper interagency coordination continue to be major problems in many states and communities, despite the oft-documented failure of traditional, isolated systems to offer an adequate range of service needs among the client population. Denial of the basic legal and human rights of retarded persons frequently is grounded in the failure of society to develop service delivery systems which are multi-faceted, make available to the retarded a wide range of generic and specialized health, education and social services and build in workable mechanisms for client-centered case management and interagency cooperation.

It is important to recognize that attempts to deliver direct services to mentally retarded clients often involve the real or potential denial of one or more of the individual's rights or prerogatives. For this reason, it is incumbent on responsible professionals to employ intervention strategies which minimize the degree of infringement on the client's rights without sacrificing the likelihood of positive outcomes.¹

Inherent in this emphasis on minimal intervention are several important, underlying assumptions, on the part of the American Association on Mental Deficiency, about mental retardation and society's responses to the problem. First, no right or privilege should be withheld from any citizen without a convincing justification; at the same time, denying mentally retarded individuals access to appropriate services on rigid civil libertarian grounds is no solution to the problem. Indeed, inaction may be a cruel form of inhumanity to an individual desperately in need of assistance. Second, in view of the complexity and diversity of the assistance needed by persons classified as mentally retarded, habilitation services must be individually tailored and packaged to meet the needs of each particular client. No restriction should be placed on a client's rights or privileges by a service agency or individual practitioner unless it can be clearly demonstrated that the restriction is an essential prerequisite to accomplishing an approved service goal. The fact that it may be necessary to limit the exercise of a particular right of a client in an effort to achieve a service goal, however, is insufficient grounds for withholding

¹ In the legal context, this principle is often referred to as the "least restrictive alternative." Over the past few years, as the result of a flurry of federal and state lawsuits asserting the "right to treatment" and the "right to education" for all mentally retarded individuals, the concept of the least restrictive alternative has been added to the lexicon of most professionals in the field. However, the meaning of the term itself frequently has been confined to physical restrictions on an individual's freedom, whether in an inappropriate educational setting (e.g., a segregated classroom) or in a residential milieu (e.g., a sterile, custodial institution). It should be made clear that the concept of minimal intervention, as it is used in this position statement, applies equally to the service or treatment modalities selected by the program staff as well as the physical environment in which the program takes place.

any other right or privilege of that individual. Finally, the impact of mental retardation is dynamic in nature and, therefore, often will have differential effects at various points in the retarded individual's life. The service delivery system must be flexible enough to adjust to such changes and restore individual rights and privileges as soon as they can be properly exercised by the client. The purpose of this statement is to specify the service rights of mentally retarded individuals and to articulate the views of AAMD concerning the principles underlying an effective, balanced and comprehensive approach to delivering a full range of habilitative services to such persons.

II The Individual's Right to Service

As the Association stressed in an earlier position statement, "mentally retarded individuals have the right to a publicly supported and administered comprehensive and integrated set of habilitative programs and services designed to minimize handicap or handicaps."² Among the service rights specifically recognized by the Association are:

- A. The right to a free public education appropriate to the individual's needs;
- B. The right to quality medical care;
- C. The right, in accordance with a written, individualized program plan, to such training, rehabilitation, habilitation, therapeutic and counseling services as will assist the individual to develop to his or her maximum potential;
- D. The right to engage in productive labor or other meaningful activities to the extent of his or her capabilities;
- E. The right to assistance in securing access to appropriate services and exercising his or her full rights as citizens;
- F. The right of the retarded individual to exercise freedom of choice in the selection of services, to the extent of his or her capability;
- G. The right to a physical and social environment conducive to the development and growth of the individual and the full exercise of the rights listed above.
- H. The right of the client or his or her parent, guardian or legal representative to have access to all personal service records, data and information maintained by any service agency.

An effective service delivery system should be designed to secure and safeguard the above rights.

² See Rights of Mentally Retarded Persons.

III Elements of an Effective Service Delivery Network

Mentally retarded persons, like other citizen's³ have health, education and social service needs which must be met. While the range and diversity of these needs often exceed those of the average American, the services required to meet them must be viewed as an integral part of the total spectrum of the human service programs provided by society. The mistake of the past has been to overemphasize the separation of mental retardation service systems and, thus, isolate the retarded from the mainstream of society and exaggerate their deviancy from societal norms.

Due to variations in population, geography and socio-political factors, it is impossible to specify, with any degree of precision, a universal model for organizing a service delivery system for the mentally retarded which will be equally applicable to any state or local jurisdiction. Nonetheless, the Association believes that any comprehensive effort to furnish mentally retarded individuals with the range of human services they may require across time must adhere to the following basic organizaing principles:

- A. Compensatory Rights. Depending on the nature and degree of their handicaps, mentally retarded persons are, to a greater or lesser extent, unable to enjoy fully the rights and privileges offered by society to other American citizens. Under the circumstances, the Association believes that retarded individuals should be entitled to receive specialized services or special adaptations of existing services which are designed to assist them in exercising their full citizenship rights and privileges. Such compensatory services should:
 1. be as close to the accepted norms of society as possible, given the nature and degree of the individual's handicap(s) and the social and cultural milieu in which services are to be delivered;
 2. be offered in as normal a physical setting as possible, given the client's age, sex and degree of disability;
 3. employ intervention techniques which minimize the degree of infringement on the individual client's rights and privileges without sacrificing the prospect of positive, goal oriented results;
 4. provide an appropriate balance between changes in environment and alterations in behavior in an effort to assist the retarded individual to adjust to his or her surroundings.
- B. Individualized Program Plan. A written, individualized program plan should be developed on every mentally retarded person in need of rehabilitative services. This plan should be based on an in-depth, multi-disciplinary evaluation of the client's service needs and should specify appropriate long-range goals and short-term service objectives as well as specific techniques for accomplishing these goals and objectives. Provision for periodic re-evaluation of the client and his or her service goals and objectives should be built into the plan.

³ The word "citizen" is used in this paper to underline the basic civil rights of persons who are mentally retarded. However, it should be interpreted to include aliens who are legally entitled to services as well as natural and naturalized citizens of this country.

An agency with general responsibility for case management or the agency with primary responsibility for delivering services to the particular client should assume responsibility for developing the individual's program plan. In either case, it is essential that the plan contain an integrated set of strategies for addressing all of the client's service needs and not be limited to the services being delivered by the lead agency. It is also important that the plan is accurately and currently maintained so that it is viewed by direct care as a useful, working document rather than the imposition of unnecessary paperwork by a distant bureaucracy.

Recipients of services and their personal or legal representatives should be given a full opportunity to participate in all phases of the development and review of their individual program plan. Where appropriate, parents should be asked to participate in carrying out the plan, as well.

The basic plan should be a readable document, easily understood by parents and others who have a legitimate concern about the progress of the client. In addition, the format of the plan should be designed to facilitate the utilization of modern data retrieval systems and, thus, permit the rapid assessment of intervention techniques and, ultimately, the performance of service systems. Included in all such systems must be adequate safeguards against invasions of the client's right to privacy.

Finally, each client should be assigned a client program coordinator to assist him or her in accessing appropriate services and assuring that the individualized program plan is carried out adequately. Such a coordinator must be knowledgeable about the service options open to his client and willing and able to advocate on the client's behalf for the most appropriate and highest quality service or combination of services.

- C. Organization of Services. Traditionally, in American society, human services have been organized along disciplinary lines. Physicians, nurses and other health professionals have delivered health services; teachers have provided educational services and social workers, social services. Until recent years, this vertical model of delivering health, education and social services has worked rather well for most citizens with unidimensional service needs (e.g., the sick patient or the "average" student, etc.).

But, despite recent efforts to establish linkages between existing health, education and social services agencies, the current approach to delivering human services to the mentally retarded, the elderly, the disadvantaged and other groups with multiple service needs has been largely unsuccessful. The shortcomings of current delivery systems can be traced to the lack of integrated service goals and objectives and the resultant fragmentation in service delivery. A closely related problem has been the tendency to define service objectives and program boundaries in terms of agency goals (both formal and informal) rather than in terms of client needs.

The Association recognizes the legitimacy of assigning appropriate responsibilities for mental retardation services to generic service agencies at the state and local level which possess broad expertise in the areas of health, education or social services. We also appreciate the fact that each state or local government will have to adopt an organizational structure which fits its own particular needs. Nonetheless, there are certain basic organizing principles which should be observed, including:

1. The role and responsibilities of each public agency serving the mentally retarded, either directly or in a supportive capacity, should be clearly delineated. In addition, the state's overall organizational plan should take cognizance of the direct and indirect services provided by private non-profit and proprietary organizations and by institutions of higher education; efforts should be directed at making effective use of such resources as part of a comprehensive statewide service network.

The chief executive officer of the state or local jurisdiction should be responsible for reviewing the adequacy of the current organizational structure and assuring that all functional responsibilities related to mental retardation services are clearly assigned and adequately carried out.

2. Any delegation of responsibility for serving the mentally retarded should be accompanied by sufficient authority and resources (both fiscal and human) to carry out the particular program or activity.
3. The needs of the client, rather than the needs of the service agency, its staff or volunteers, should be the central principle around which all services to the retarded are organized. The individual program plan should be used as a tool in achieving this basic reorientation in the design of service delivery systems.
4. Every effort should be made to maximize the utilization of generic community resources. Thus, when new or expanded services are required to meet the needs of retarded persons, first priority should be given to attempts to involve appropriate generic agencies; specialized services or programs should be established only where the interest, resources and/or technical expertise of the generic service agency - even with appropriate augmentation - is insufficient to carry out a high quality program.
5. Regardless of how a particular jurisdiction decides to organize services for mentally retarded persons, it is vital that staff with sufficient knowledge and expertise about the special problems associated with mental retardation are employed at all levels of government - state, regional and local - where decisions affecting the lives of retarded persons are being made.

D. Planning, Coordination and Evaluation of Services. As indicated above, the longitudinal needs of persons afflicted by mental retardation dictate the need to involve many types of human service agencies. However, as more and more agencies have begun to serve mentally retarded persons, the task of guiding the client, especially the client with multiple service needs - through the maze of service agencies has become exceedingly difficult. Failure to provide proper linkages between programs, interagency jealousies and bickering and the lack of clearly defined lines of responsibility have led to frustration for clients in their search for services.

An effective and efficient service delivery system should involve the following elements:

1. A regular mechanism for interagency coordination at each level of government serving the mentally retarded.
2. A regular means of obtaining and acting on citizen input concerning the administration and management of state, regional or local programs for mentally retarded individuals. This system, which might take the form of a citizen's advisory committee or a similar body, should serve as a forum for encouraging interested citizen groups and individuals to express their views. The responsible agency official should be prepared to act on legitimate citizen complaints and worthwhile suggestions.
3. A statewide system for collecting and analyzing relevant data on the effectiveness of service programs and agencies throughout the state. A client data system, which can be used in assessing the degree of developmental progress compared to the objectives set out in the clients' individualized program plans, will be particularly valuable in making such judgments about the quality of service programs and will provide a means of holding responsible officials accountable.
4. A statewide network of information and referral agencies should be established in each state to channel clients to needed services in the most expeditious manner. An aggressive program of early casefinding must be an integral part of this effort.
5. A client-centered case management system which is capable of assessing the needs of retarded individuals in its catchment area over time and assuring that they have access to appropriate counseling, direct and supportive services.
6. A mechanism for providing personal advocacy services on behalf of mentally retarded individuals who require such assistance.
7. Procedures for assuring relative equity in the distribution of service programs within the particular jurisdiction.
8. Procedures for assuring that programs designed to serve minority groups in the society are culturally acceptable to the target population.

USE OF PHYSICAL, PSYCHOLOGICAL AND PSYCHO-PHARMACOLOGICAL
PROCEDURES TO AFFECT BEHAVIORS OF MENTALLY RETARDED PERSONS

I Introduction

Growing concern for the human rights of mentally retarded individuals over the past several years has resulted in a greater awareness of the need to scrutinize closely the programmatic procedures used in working with retarded clients. Particular attention has been focused on techniques designed to influence client behaviors. These techniques may be categorized as follows:¹

- A. Physical techniques, including deliberate modifications of environment and of the individual's place in the environment;
- B. Psychological principles applied in a systematic manner to affect behaviors; and
- C. Psycho-pharmacological agents given for the purpose of affecting behaviors.

It has long been recognized that the effects of the environment on human behavior, whether through planned systematic intervention or the lack of intervention, have far reaching consequences which may, at times, be irreversible. Recent refinements in our understanding of the principles of human behavior have rendered such behavior intervention techniques increasingly effective. If properly applied, most professionals would agree that these techniques have significant potential for helping mentally retarded persons to develop their abilities. However, the degree of control possible over other human beings requires a careful review of the attendant ethical and moral questions concerning behavior modification, behavior shaping drugs, and similar intervention techniques.

All individuals in our complex society are vulnerable to violations of their rights. However, the likelihood of having their rights violated is greater for individuals who are mentally retarded not only because they are less able to speak on their own behalf, but also because they are more dependent for assistance in daily living on other individuals and social systems whose motivations and responsibilities are influenced by demands aside from the clients' interests.

When making decisions connected with a client's service plan, every practitioner should, as a matter of course, take measures which assure that the client's rights are safeguarded. At the same time, mentally retarded individuals should not be deprived of potentially effective services; and, therefore, qualified practitioners should not be instilled with such caution that their mentally retarded clients are denied access to needed services. Practitioners must take into account the vulnerability of this population when planning and administering any part of an

1 The complex area of psycho-surgery is beyond the scope of this paper.

individual's over-all program plan.² While careful review procedures similar to those outlined below are essential, perhaps one of the better safeguards against rights violations is empathy. Practitioners should ask themselves, would you agree to the identical treatment for yourself?

The purpose of this document is to outline procedures for prevention of abuse while encouraging the use of these techniques to assist mentally retarded individuals to achieve life-enriching goals.

II Individual Plans

All agencies or organizations rendering direct services to mentally retarded individuals should have policies and procedures which incorporate the following:

A. Implementation of programs should take place only after there is written documentation of required approvals of goals, techniques and design of the program in accordance with the procedures outlined in Section III of this policy statement.

B. There should be routine, active participation by the client in selecting his or her own program goals and techniques³ with consultation as necessary from parents, guardians, or legal representatives. The client's consent should be obtained based upon a reasonable assurance that he or she understands the program's objectives, procedures, rationale, and any alternative approaches available; in addition, the client should be permitted to withdraw consent at any stage of the program and be fully informed in advance of his or her right to do so.

C. There should be a periodic reassessment of every client's habilitation plan by his or her program coordinator. Goals and techniques should be considered separately to assure that the combination selected⁽¹⁾ fits logically into the client's comprehensive, individually tailored habilitation plan and (2) is a minimal intervention strategy consistent with reasonable and optimistic expectations of improvement in the client's ability to function independently.

D. There should be up-to-date written documentation of the status of the client's comprehensive individually tailored habilitation plan.⁴ Such documentation should include:

(1) the identification of current priorities among the client's service goals, including appropriate justification;

² Obtaining a client's informed consent or that of the client's surrogate is an important means of safeguarding an individual's rights. Because informed consent is a central consideration in a variety of circumstances (e.g., sterilization, guardianship, involvement in research projects, etc.) a separate position paper defining and spelling out the application of informed consent with mentally retarded clients currently is being prepared by the Association.

³ The rights of the mentally retarded individual to make decisions which affect his or her life, and to have others intervene in such decisions only to the extent that the individual's ability to represent his or her own interests is impaired, is discussed more fully in the AAMD policy statements, "Guardianship for Mentally Retarded Persons" and "The Right to Habilitation for Persons who are Mentally Retarded."

⁴ See AAMD Policy Statement on "The Right to Habilitation for Persons who are Mentally Retarded."

(2) the rationale for selection of intervention strategies to achieve such goals;

(3) records documenting the client's progress toward goals with an interpretation of the effectiveness of the intervention strategy applied; and

(4) evidence that priorities are altered in keeping with the client's growth and development.

Ongoing clinical documentation is a major source of evaluative data to: (a) the practitioner, the client, and the client's representative; (b) responsible governmental or non-governmental officials within the administrative hierarchy in which the practitioner functions as well as other administrative and judicial review bodies to which he or she may be accountable; and (c) research scientists.

E. The use of techniques to influence a client's behavior for the convenience of staff and without particular, planned benefit to the client is not acceptable and should be prohibited.

F. Supervision of each aspect of a program should be the responsibility of a qualified and competent person and should be monitored by the client's program co-ordinator.⁵

III Review Procedures

All programs designed to influence behavior should undergo review on an individual or class basis by at least two bodies:

1. A professional review body which should determine the appropriateness and validity of the goals and techniques; and
2. A human rights review and protection board⁶ which shall assess the ethical and legal implications of the proposed behavioral goals and the validity of the procedures for obtaining informed consent.

In addition, techniques considered to be experimental in nature should be reviewed by a research review committee consisting of qualified research scientists who are competent to judge the merits of the proposal and the validity of the research design.

In order to conceptualize the gradations of review proposed, a classification of goals and techniques according to the type of review each would receive is discussed below:

A. Classification of Goals for Review. Goals should be considered in terms of their uniqueness or universality. In general, the more unique the goal, the more stringent the review should be. Two types of goals, requiring different types of review, are described below:

⁵ See The Right to Habilitation for Persons Who Are Mentally Retarded.

⁶ See Human Rights Review and Protection Boards.

1. Generally Acceptable Goals. On the basis of review by the professional review body and the human rights review and protection board, some behavioral goals will be approved as generally valid and applicable; these goals will require periodic reevaluation, but no additional review procedures.
2. Controversial Goals. Certain other behavioral goals will require additional review whenever they are considered for individuals or groups of individuals. The review procedures should include (a) obtaining the informed consent of the individual; (b) evidence of participation of the mentally retarded individual or his or her representative in establishment of goals; and (c) specified time periods for the review of the appropriateness of such goals.

Commentary: Goals which might receive blanket endorsement of review bodies are those which are highly valued and generally sanctioned by society. Examples of such goals would include acquiring: (a) developmental skills such as toileting, self-dressing and self-feeding; (b) social skills such as language and communication, cooperative behavior and certain work-related behaviors; (c) culturally desirable skills such as work skills, recreation skills, and skills related to mobility (bicycling, skating). Another example of generally sanctioned goals would be the elimination of behaviors which cause the client suffering, pain or harm, such as decreasing hyperactivity, alleviating severe depression, reducing severe and chronic anxiety, or eliminating physically self-damaging behavior. Programs should be designed to develop behaviors, not simply to remove them.

In some cases, review bodies might endorse certain goals as generally acceptable only for individuals enrolled in specific programs. Written entry requirements should be clearly stated in such cases.

Examples of goals which should be examined on an individual basis are: (a) elimination of hallucinations; (b) elimination of seizures; (c) development of legal or non-injurious patterns of sexual behavior; (d) de-escalation of certain forms of aggressive or competitive behaviors; (e) development of socially acceptable types of affiliative behavior (loving parents); (f) strengthening or weakening certain types of assertive behaviors in determining the desirability of such goals information concerning the medical, social, psychological and/or the physical environment of the individual should be assessed.

B. Classification of Techniques for Review. Techniques should be examined in terms of their location on the following three continua: safety vs. danger to the client, enhancement vs. dehumanization of the client, and demonstrated efficacy vs. experimental nature of the procedure. In general, the greater the risk in the use of a technique, the more stringent the review should be and the more restrictive the use. Three types of techniques have been identified which require different types of review:

1. Generally Acceptable Techniques.⁷ On the basis of an assessment by the professional review body and the human rights review and protection board, some techniques which influence behavior will be approved as generally valid and applicable; such techniques will require periodic reevaluation but no additional review procedures before they are applied. Common types of psychological, physical and pharmacological interventions are included in this category.
2. Controversial Techniques. Certain techniques for influencing behaviors may involve elements of risk, pain or infringements. In such instances more stringent review procedures should be imposed including (a) obtaining the informed consent of the individual; (b) evidence of participation of the recipient in the selection of techniques; (c) specific time periods for review of the effectiveness of such techniques as well as a system for minimizing risks; and (d) a procedure to appeal the decision of a review body. When considering the endorsement of these techniques in a program, a review body should weigh the likelihood of a long-term consequence which might be an undesired by-product of exposure to risk, pain or infringement on dignity.
3. Experimental Techniques. Certain other techniques which may be proposed for influencing behaviors should be designated as "experimental procedures" because there is limited supportive evidence concerning their efficacy. Such techniques should be used only when they are judged to be in the best interest of the individual, and then only under conditions where their consequences can be carefully controlled under competent professional supervision. Experimental control methods should be employed to verify the relation of the experimental technique to the achievement of the client's goal. For such procedures, in addition to review procedures employed for controversial techniques under III B, above, a written research proposal should undergo review by a qualified researcher(s) to evaluate the scientific merits of the proposal and the validity of the experimental design of the study proposed.

Commentary: In all cases, techniques should be applied by persons trained to meet minimum standards of competency under the supervision of a practitioner who is thoroughly knowledgeable and competent in the application of the particular techniques.⁸

Examples of psychological techniques⁹ which are likely to fall into the "generally acceptable" category are (a) positive social reinforcers such as verbal approval, smiles and, for children, hugs; (b) extinction; and (c) contingent observation.

7 Even generally acceptable techniques are objectional to some individuals on religious or other personal grounds. Clients or their representatives should have the right to refuse any form of treatment or intervention when they feel it violates such religious or personal convictions. The client or his or her representative should be apprised of the possible consequences of such refusal and appropriate remarks should be entered in the client's records and witnessed by the client or his or her representative.

8 Suggested standards of competency appear in the Florida Guidelines for the Use of Behavioral Procedures in State Programs for the Retarded, May, Jack G., Jr., et al, 1974.

9 Because terminology is subject to interpretation, every technique which the local review body catagorizes as generally acceptable, controversial or experimental should be operationally defined to accurately reflect the meaning intended by the review body.

Examples of controversial techniques which should be subject to review for each individual include restraints when life is not threatened, aversive conditioning, time out, seclusion,¹⁰ and, perhaps, overcorrection and educational fines. This category also applies when drugs are prescribed above recommended dosage or where there are legitimate differences in clinical judgment regarding correct dosage of certain drugs.

Life-protecting techniques which interfere with physical self-destruction by the temporary use of restraining methods should be readily available but ought to be time-limited options within a behavior-building program. Each occasion of use should be reported to the review bodies, and frequent use should result in re-examination of the client's entire program.

Examples of techniques requiring research review include acupuncture, certain forms of biofeedback, direct electrical stimulation of the brain, and prescription of drugs released by FDA for clinical investigation but not for clinical use. The prescription of drugs which have not received FDA clearance should be prohibited.

There is no absolute break in the continuum of what constitutes research and what constitutes services. Therefore, it is important that there be documented recognition and justification by practitioners when a strategy is employed for an individual in untested circumstances, and that clinical documentation of the effects of the intervention be recorded.

IV Definitions

For the purpose of this paper the following definitions apply.

A. Experimental procedure - A technique used with a clinical objective for an individual when its efficacy has not been generally established and accepted within the profession prescribing its use.

B. Research - Scientific investigation designed to reveal (a) the mechanism by which a process works (basic) or (b) the efficacy of a procedure under specified conditions (applied).

C. Physical technique - Any deliberate restriction of physical freedom designed to modify behaviors of an individual or group of individuals. Includes but is not limited to physical restraints, removal of an individual from one setting to another temporarily or permanently, and mechanically limiting freedom of movement.

D. Psycho-pharmacological agents - Those drugs prescribed for the purpose of influencing behavior.

E. Psychological technique - Deliberate application of procedures designed to achieve specific behavioral objectives. Includes but is not limited to positive reinforcement, contingency management, token economy, flooding, systematic desensitization, aversive stimulation, extinction, suggestion and hypnosis, and psychotherapy.

¹⁰ Accreditation standards applicable to management of maladaptive behavior appear in Section 2.1.8 of the New and Revised Standards for Residential Facilities, as modified on November 14, 1974, published by the Joint Commission on Accreditation of Hospitals.